Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

NATIONAL GUIDELINE CLEARINGHOUSE

General

Guideline Title

Best evidence statement (BESt). Sibling support in end of life care.

Bibliographic Source(s)

Cincinnati Children's Hospital Medical Center. Best evidence statement (BESt). Sibling support in end of life care. Cincinnati (OH): Cincinnati Children's Hospital Medical Center; 2011 Jun 7. 5 p. [10 references]

Guideline Status

This is the current release of the guideline.

Recommendations

Major Recommendations

The strength of the recommendation (strongly recommended, recommended, or no recommendation) and the quality of the evidence (1a-5b) are defined at the end of the "Major Recommendations" field.

It is recommended that siblings of actively dying children be involved and prepared for their siblings' death to facilitate appropriate grief responses (Lauer et al., 1985 [4a]; Freeman, O'Dell, & Meola, 2003 [4a]; Pettle Michael & Lansdown, 1986 [4b]; Martinson et al., 1990 [4b]; Nolbris & Hellstrom, 2005 [4b]; Bendor, 1989 [5a]; Heiney, 1991 [5a]; Carr-Gregg & White, 1987 [5a]; Duncan, Joselow & Hilden, 2006 [5b]; Giovanola, 2005 [5b]).

Definitions:

Table of Evidence Levels

Quality Level	Definition
1a† or 1b†	Systematic review, meta-analysis, or meta-synthesis of multiple studies
2a or 2b	Best study design for domain
3a or 3b	Fair study design for domain
4a or 4b	Weak study design for domain
5	Other: General review, expert opinion, case report, consensus report, or guideline

†a = good quality study; b = lesser quality study

Table of Recommendation Strength

Strength	Definition
"Strongly recommended"	There is consensus that benefits clearly outweigh risks and burdens (or visa-versa for negative recommendations).
"Recommended"	There is consensus that benefits are closely balanced with risks and burdens.
No recommendation made	There is lack of consensus to direct development of a recommendation.
Dimensions: In determining the strength of a recommendation, the development group makes a considered judgment in a consensus process that incorporates critically appraised evidence, clinical experience, and other dimensions as listed below.	
1. Grade of the Body of Evidence (see note above) 2. Safety/Harm 3. Health benefit to patient (direct benefit) 4. Burden to patient of adherence to recommendation (cost, hassle, discomfort, pain, motivation, ability to adhere, time) 5. Cost-effectiveness to healthcare system (balance of cost/savings of resources, staff time, and supplies based on published studies or onsite analysis) 6. Directness (the extent to which the body of evidence directly answers the clinical question [population/problem, intervention, comparison, outcome]) 7. Impact on morbidity/mortality or quality of life	

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

- Grief response
- Bereavement

Guideline Category

Management

Clinical Specialty

Family Practice

Pediatrics

Psychiatry

Psychology

Intended Users

Advanced Practice Nurses

Nurses

Physician Assistants

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Guideline Objective(s)

To evaluate, among siblings of actively dying patients, if sibling involvement and preparation at patient's end of life compared to no involvement and preparation impacts the siblings' grief response

Target Population

Siblings 3-21 years of age of terminally ill children at patient's end of life

Interventions and Practices Considered

Sibling preparation and involvement at patient's end of life

Major Outcomes Considered

Grief response

Methodology

Methods Used to Collect/Select the Evidence

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

Search Strategy

Terms: grief, children, sibling, death

Databases: PubMed, Medline, Google Scholar, CINAHL

No date limits used. Last search: 3/17/11

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Table of Evidence Levels

Quality Level	Definition
1a† or 1b†	Systematic review, meta-analysis, or meta-synthesis of multiple studies
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†a = good quality study; b = lesser quality study

Methods Used to Analyze the Evidence

Systematic Review

Description of the Methods Used to Analyze the Evidence

Not stated

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

Not stated

Rating Scheme for the Strength of the Recommendations

Table of Recommendation Strength

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Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

Peer Review

Description of Method of Guideline Validation

Reviewed against quality criteria by two independent reviewers

Evidence Supporting the Recommendations

References Supporting the Recommendations

Bendor SJ. Preventing psychosocial impairment in siblings of terminally ill children. Hosp J. 1989;5(3-4):153-63. [34 references] PubMed

Carr-Gregg M, White L. Siblings of paediatric cancer patients: a population at risk. Med Pediatr Oncol. 1987;15(2):62-8. [79 references] PubMed

Duncan J, Joselow M, Hilden JM. Program interventions for children at the end of life and their siblings. Child Adolesc Psychiatr Clin N Am. 2006 Jul;15(3):739-58. PubMed

Freeman K, O'Dell C, Meola C. Childhood brain tumors: children's and siblings' concerns regarding the diagnosis and phase of illness. J Pediatr Oncol Nurs. 2003 May-Jun;20(3):133-40. PubMed

Giovanola J. Sibling involvement at the end of life. J Pediatr Oncol Nurs. 2005 Jul-Aug;22(4):222-6. [34 references] PubMed

Heiney SP. Sibling grief: a case report. Arch Psychiatr Nurs. 1991 Jun;5(3):121-7. PubMed

Lauer ME, Mulhern RK, Bohne JB, Camitta BM. Children's perceptions of their sibling's death at home or hospital: the precursors of differential adjustment. Cancer Nurs. 1985 Feb;8(1):21-7. PubMed

Martinson IM, Gilliss C, Colaizzo DC, Freeman M, Bossert E. Impact of childhood cancer on healthy school-age siblings. Cancer Nurs. 1990

Jun;13(3):183-90. PubMed

Nolbris M, Hellstrom AL. Siblings' needs and issues when a brother or sister dies of cancer. J Pediatr Oncol Nurs. 2005 Jul-Aug;22(4):227-33. PubMed

Pettle Michael SA, Lansdown RG. Adjustment to the death of a sibling. Arch Dis Child. 1986 Mar;61(3):278-83. PubMed

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for each recommendation (see the "Major Recommendations" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Supporting siblings at the time of death of their brother or sister can promote normal growth and development and facilitate healthy adjustment to the loss.

Potential Harms

Not stated

Qualifying Statements

Qualifying Statements

This Best Evidence Statement addresses only key points of care for the target population; it is not intended to be a comprehensive practice guideline. These recommendations result from review of literature and practices current at the time of their formulation. This Best Evidence Statement does not preclude using care modalities proven efficacious in studies published subsequent to the current revision of this document. This document is not intended to impose standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to this Statement is voluntary. The clinician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.

Implementation of the Guideline

Description of Implementation Strategy

An implementation strategy was not provided.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Staying Healthy

IOM Domain

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

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Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2011 Jun 7

Guideline Developer(s)

Cincinnati Children's Hospital Medical Center - Hospital/Medical Center

Source(s) of Funding

Cincinnati Children's Hospital Medical Center

Guideline Committee

Not stated

Composition of Group That Authored the Guideline

Group/Team Members: Tina Ulanowski, M.Ed., CCLS, Cincinnati Children's Hospital Medical Center StarShine Hospice and Palliative Care; Susan McGee, MSN, RN, CNP, Division of Developmental and Behavioral Pediatrics; Barbara Giambra, MS, RN, CNP, Evidence-based Practice Mentor, Center for Professional Excellence, Research, and Evidence-based Practice

Financial Disclosures/Conflicts of Interest

Not stated

Guideline Status

This is the current release of the guideline.

Guideline Availability

Electronic copies: Available from the Cincinnati Children's Hospital Medical Center .

Print copies: For information regarding the full-text guideline, print copies, or evidence-based practice support services contact the Cincinnati Children's Hospital Medical Center Health James M. Anderson Center for Health Systems Excellence at EBDMInfo@cchmc.org.

Availability of Companion Documents

The following are available:

- Judging the strength of a recommendation. Cincinnati (OH): Cincinnati Children's Hospital Medical Center; 2008 Jan. 1 p. Available from the Cincinnati Children's Hospital Medical Center .
- Grading a body of evidence to answer a clinical question. Cincinnati (OH): Cincinnati Children's Hospital Medical Center; 1 p. Available from the Cincinnati Children's Hospital Medical Center .
- Table of evidence levels. Cincinnati (OH): Cincinnati Children's Hospital Medical Center; 2008 Feb 29. 1 p. Available from the Cincinnati Children's Hospital Medical Center .

Print copies: For information regarding the full-text guideline, print copies, or evidence-based practice support services contact the Cincinnati Children's Hospital Medical Center Health James M. Anderson Center for Health Systems Excellence at EBDMInfo@cchmc.org.

Patient Resources

None available

NGC Status

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